

Governor's Commission on Mental Retardation

**Prioritization and the Intake and Eligibility Process of
State Developmental Disability Agencies:
A National Study of Strategies to Reduce the
Waiting List for Adult Services**

A Staff Report

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The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Richard E. Vincent

Staff Members:

Barbara Mazzella
Emily Micolonghi

Principal Author: Barbara Mazzella

The Commission is especially grateful to Allison Cohen for her assistance in the development of this project.

The Governor's Commission on Mental Retardation
One Ashburton Place – Room 805
Boston, MA 02108
(617) 727-0517

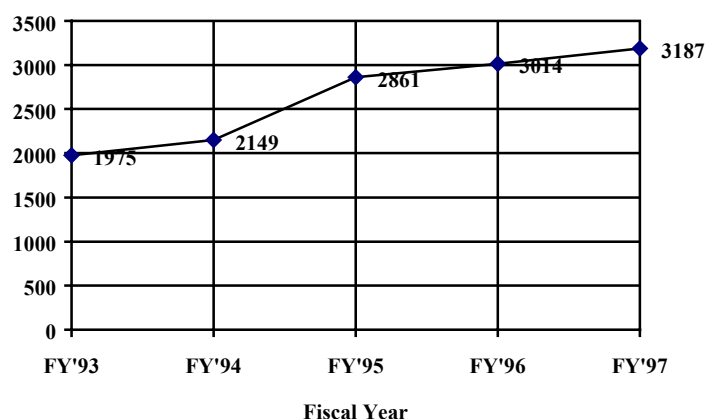
Volume 2, 2, September 1998
The Commonwealth of Massachusetts

**PRIORITIZATION AND THE INTAKE AND ELIGIBILITY PROCESS OF
STATE DEVELOPMENTAL DISABILITY AGENCIES:
A NATIONAL STUDY OF
STRATEGIES TO REDUCE THE WAITING LIST FOR ADULT SERVICES**

Introduction

The waiting list is the most persistent public policy issue facing the Massachusetts service delivery system for adults with mental retardation. In Massachusetts alone, there are nearly 3,000 individuals who are waiting for day or residential services. This number continues to grow. The Massachusetts Department of Mental Retardation concludes that the waiting list will expand by 13% annually (Facing the Waiting List Challenge: Responding to the Needs of Individuals and Families, 1996). Table 1 illustrates the steady growth in the waiting list population over the course of the past five years.

Table 1
Massachusetts Unserved Waiting List History



One of the few consolations that Massachusetts can find in addressing the needs of thousands of persons with mental retardation waiting for services is that it is not alone. In 1987, the Arc of the United States surveyed state directors of MR/DD services and found 63,634 individuals with mental retardation waiting for residential services and 76,039 waiting for day/vocational services for a total of 139,673 services needed. In 1997, the Arc of the United States re-examined the status of waiting lists reported by states for community services across the country. “The total services needed by individuals in communities is 218,186 in 1997 in the 48 states reporting waiting list information...to describe the waiting list situation as a crisis for America is no exaggeration” (Davis, 1997).

Recognizing that resolution of waiting lists will only occur when stakeholders examine the entire service delivery system and develop a better understanding of the complexities of waiting lists, the

staff of the Massachusetts Governor's Commission on Mental Retardation conducted a survey of intake, eligibility, and prioritization procedures.

Method of Study

In June 1997, letters were sent to each of the fifty state mental retardation/developmental disability agencies seeking information on eligibility determination, prioritization for service delivery, and criteria for monetary awards. Specifically, the request asked the following questions:

- Who maintains current waiting lists?
- Do states maintain written or informal policies regarding prioritization for service delivery?
- What are the factors that determine eligibility?
- What "designated groups" place additional pressures on the service system?
- Which strategies or models for financing community services have been effective in reducing waiting lists?

The process of obtaining, screening, and verifying states' data took place between June 12, 1997 and September 30, 1997. To insure that information was obtained from each state, follow-up phone calls were made to agencies that did not respond to the initial mailing. A total of 32 states (64%) responded with information regarding waiting lists, prioritization and eligibility. The nature and quality of information varied considerably from state to state. Eleven states (34%) provided detailed information regarding "waiting list criteria" and definitions of priority levels, whereas 18 states (56%) provided limited information regarding specific guidelines or strategies. In addition, three states (9%) included information indicating that either "waiting list policy decisions" were under review or that waiting lists were not maintained.

Results

The findings reveal similarities in each state's approach to the waiting list.

Type of Agencies that Maintain Waiting Lists

A preliminary step in planning for individuals on the waiting list is identifying who is responsible for maintaining data. As presented in Table 2, 29 states maintain waiting lists, and 3 states do not maintain lists (KS, CA, IL). Of the 29 states that maintain lists, 14 states have a single state agency collect the information, 4 rely on a regional or district agency (GA, MS, MO, WA), 5 use a county agency (AL, MI, MN, OH, PA) and 2

contract with private service providers to collect information (NH, NY). Three states report that waiting lists are “systemic problems” but did not clearly indicate whether they maintain lists (DC, ND, TX). In addition, one state (CT) maintains waiting list information at both the regional and central DMR office.

STATE	TYPE OF AGENCY				OTHER RESPONSES		
	STATE LEVEL	REGIONAL/ DISTRICT LEVEL	COUNTY LEVEL	SERVICE PROVIDERS	DID NOT RESPOND	NO WAIT LIST	LIMITED INFO
AL			✓				
AK					✓		
AZ					✓		
AR	✓						
CA						✓	
CO					✓		
CT	✓	✓					
DE					✓		
DC							✓
FL	✓						
GA		✓					
HI					✓		
ID					✓		
IL						✓	
IN					✓		
IA					✓		
KS						✓	
KY	✓						
LA					✓		
ME					✓		
MD					✓		
MA	✓ ¹						
MI			✓				
MN			✓				
MS		✓					
MO		✓					
MT	✓						
NE	✓						

¹ Massachusetts data not included in tally of respondents.

STATE	TYPE OF AGENCY				OTHER RESPONSES		
	STATE LEVEL	REGIONAL/ DISTRICT LEVEL	COUNTY LEVEL	SERVICE PROVIDERS	DID NOT RESPOND	NO WAIT LIST	LIMITED INFO
NV	✓						
NH				✓			
NJ	✓						
NM					✓		
NY				✓			
NC	✓						
ND							✓
OH			✓				
OK	✓						
OR					✓		
PA			✓				
RI					✓		
SC					✓		
SD	✓						
TN	✓						
TX							✓
UT					✓		
VT	✓						
VA	✓						
WV					✓		
WA		✓					
WI					✓		
WY	✓						

- **Eligibility for Services**

Virtually all states base their eligibility criteria on state law including residency requirements and a level of care determination as evidenced by a standardized instrument such as the Inventory for Client and Agency Planning (ICAP). Only two states, Tennessee and Nebraska reported additional criteria.

Eligibility for services is dependent on whether the state uses the federal definition of developmental disability or other functional definitions. Twenty-seven percent of the state agencies report numbers of people with a particular developmental disability (e.g., mental retardation and autism) who are waiting for services but have no data at all on persons with other types of disabilities.

Tennessee has different mechanisms for determining eligibility depending on the service and the funding source. For state-funded day service options, early intervention and family support, eligibility is established by the service provider and is then reported to the Division of Mental Retardation Services. The Division monitors a sampling of this information during annual surveys of the agency. For state-funded residential services and all services funded through the Medicaid Home and Community-Based Waiver, the Division's Regional Offices establish eligibility.

In Nebraska, the Developmental Disabilities Services Act, passed in 1991, serves as the foundation for eligibility and prioritization policies. In 1995, the state offered day services to all eligible students graduating from high school at age 21; since July 1, 1996, service coordination also has been available to all persons determined eligible for developmental disabilities services. Nebraska is able to serve these populations using resources in the form of intervention hours that are allocated based on need. The state is in the process of finalizing an assessment tool to assist teams in determining the appropriate level of funding.

- **Policies Regarding Prioritization for Service Delivery**

States were asked if they had written or informal policies for choosing the order in which persons with MR/DD will receive services. Of the 32 states that responded, 21 do not maintain written policies. The remaining eleven states (FL, MO, MT, NE, NH, NJ, OH, SC, VA, VT, WY) included specific guidelines to prioritize requests for community-based services. Eleven states have notable differences in their prioritization systems.

A. Some states prioritize on *length of time waiting*. Nevada, Oklahoma and Mississippi use the date of application as a basis for prioritizing individuals on a waiting list. These states do not maintain a formal system for determining if one applicant has a greater

priority or need for a service. Services are limited to available resources. Nevada revised their Home and Community-Based Waiver for 1997 and will be targeting new resources to “those who have been waiting the longest.”

B. Other states assess the *intensity of need*. Washington and Florida maintain waiting lists based on the date of application for services, the individual’s family or community situation and the individual’s personal health and functional status.

Florida has determined that a standardized set of procedures is necessary to provide uniformity across the state. Florida’s data collection system now accumulates data by persons and their approved costs, and reflects the gap “between intensity of funding/services needed and supports provided to the individuals” (Florida Procedure for Prioritizing Individuals in Need of Developmental Services, 1997). Florida’s “Wait List Priority Evaluation Worksheet” assigns numerical weights to three categories: client situation needs (safety issues, environmental concerns and family supports available); current wait time status (number of days since services approved); and the client’s personal level of need.

In determining the intensity of need, Connecticut also includes information regarding the ability of the individual to “wait for services.” Time frames are considered a critical component in awarding resources. Connecticut’s protocols for assigning priority status describe four levels: emergency (within 3 months), and priorities 1, 2, and 3. Residential placement plans are developed in accordance with these established priorities. When a residential resource becomes available, a search begins for the highest priority individual for whom the resource is most compatible. This frequently results in only a partial match to the individual’s needs and may result in more resources being provided than are needed by a particular individual. According to the Connecticut waiting list planning committee, “the department needs to rework this process so the needs of the individual are considered first, and supports and resources are tailored to address those needs” (Planning Report to Eliminate the DMR Waiting Lists, 1993). Connecticut also maintains a priority system for accessing day services. All of the waiting lists are reviewed at least biweekly, and regional reports are submitted annually to the Commissioner including the number of individuals served and the number of individuals on the waiting list.

New Jersey has established “waiting list procedures” (see Table 3) that describe how to prioritize placement needs when there are insufficient funds to provide the most appropriate day or residential service. The categories are based on the level of urgency, and there is no numerical ranking within each category. “[P]riority for placement is given to persons in the order in which they were added to the urgent category of the community residential waiting list” (NJ Division Circular, 1996). However, if an individual has a waiting list assignment and is having an emergency, he or she shall be removed from the waiting list and follow separate protocols as identified in New Jersey general statute.

Table 3
New Jersey Waiting List Procedures

- 1) The **Urgent category** will be assigned when the individual is in need of a placement because he or she is determined to be at significant risk. Satisfaction of one or more of the following criteria shall create a presumption that the individual is at significant risk:
- Both of the birth or adoptive parents are 55 years or older;
 - The individual is living with a person other than the birth or adoptive parents who is providing the service voluntarily and without pay and the person who has been providing care indicates that he or she can no longer care for the person with a developmental disability;
 - There is clear risk of abuse, neglect or exploitation;
 - Either of the birth or adoptive parents is under age 55 and has a chronic and/or long-term physical or psychiatric condition which limits significantly his or her ability to care for the individual;
 - Either of the birth or adoptive parents is under age 55 and there is a risk to the health or safety of the individual, parent or other individual living in the home.
- 2) The division shall assign the **Non-Urgent category** when placement is needed within two years.

Montana utilizes a screening process that prioritizes referrals based on service needs. Assessing the level of need is the first part of the screening process. The assessment form identifies nine factors including: health and safety, lack or loss of skills in current environment, lack or loss of opportunities and/or choices in current environment, loss of independence in current environment, disability level, service level, service delay, and availability of supports in the community. Each of the nine factors is reviewed and coded as severe, moderate or minimal intensity. The “service delay” factor describes waiting list categories in terms of amount of time an individual has been waiting for services, with severe being for more than three years. An individual who is rated severe is considered to be “high need” and would be referred for services and supports. The second part of the screening process requires a committee to review the appropriateness of all available vacancies. All placement decisions are to be finalized and approved through group consensus.

An integral component of Montana’s referral/screening placement process is the requirement that “every person referred for services should be placed on the list, by means of an Individual Service Record form. A master waiting list will be established which identifies all the people who have requested services and who have been referred for services. This list will also include individuals who request services in only one area of the state as well as those who wish to be considered for statewide placements.” This information is used to scrutinize the types of services which are responsive to the needs of individuals and their families.

In Vermont, funding priorities are set every three years and are reviewed annually in a System of Care Plan completed by the Division of Developmental Services with input from the community through a Developmental Services Advisory Board. The Division of Developmental Services approves

funding on an individual basis with the amount of the award determined by a review of each individual's needs and plan of service. In July 1997, Vermont completed a series of public hearings in which consumers, advocates, family members and concerned citizens provided input regarding how the state should prioritize services and funds to support individuals most in need. "This process afforded citizens the opportunity to learn how funding decisions are made and better understand the difficulty of responding to a need for services that surpasses the funds available" (Moseley, 1997). All consumers requesting services must apply through a community agency. The Division has established a funding committee, which reviews all applications and makes recommendations. The director of the division has the authority to approve, modify, or deny all requests.

Some states use a multi-tiered assessment of intensity of need. Vermont has established two levels of funding priorities. First level priorities include legally mandated services, services involving fundamental health, safety and security, and services that will enable a person to be independent. Second level priorities include supports needed to assist an individual to learn new skills, receive job support, participate in his/her community, and supports needed to move to a setting of greater independence or greater community participation, or one that will improve the individual's opportunities for growth. Vermont's waiting list population has declined as a recent restructuring of services has more effectively targeted funds to people most in need. Nevertheless, the state publicly acknowledges that "all needs cannot be met. Prioritizing client funding needs is a key responsibility of the service system."

South Carolina has established three levels of priority for residential placements for individuals on their waiting list. Priority 1 individuals are in immediate need of assistance, and admission cannot be deferred through provision of supportive services. Priority 2 individuals are experiencing medical, financial, or emotional difficulties. Priority 3 individuals will need a residential service in the future. Due to limited resources, only cases classified as Priority 1 have been considered for placement. In response to the growing numbers of cases, South Carolina now maintains a daily list of critical cases. The regional offices collaborate with the central office director of admissions to maintain accurate and updated records. There is a concerted effort to match critical cases with available resources at the local, regional, and state levels.

C. Several states indicated that they keep "*two lists*": the "waiting list" which includes people for whom beds or funding is being actively sought, and the "planning list" for people whose needs are such that the state can not serve them until the service delivery system is expanded. Many individuals and their families place their names on the "planning list" so that they can have "assurances" that a placement will be available when they need it.

In April 1997, New Hampshire formed a committee to re-examine waiting list definitions and the prioritization system for coding individuals. New Hampshire describes several tiers for individuals placed on waiting lists. Priority A are those individuals at the greatest risk for substantial physical and/or emotional harm or significant regression in developmental functioning. “It had become increasingly clear that the waiting list, particularly below the priority status level, was being used to document an individual’s future needs as a means of tracking people eligible for services.” Consequently, waiting list numbers throughout the state seemed overwhelming and a constant frustration for individuals, their families, providers of service and state policy makers. In response, New Hampshire clarified the status of individuals needing services by adopting two categories: waiting list and projected service need (see Table 4). The result has been a reduction in the numbers of individuals previously identified in their priority system, with many individuals falling into the projected service need category and others into a tracking system reflecting future needs. New Hampshire is now able to provide information to the legislature for biennial budget planning.

Table 4
New Hampshire Waiting List Proposal

Waiting List: Individuals should be placed on the waiting list if their unmet need is considered a priority and exists currently or if they will need the service within one year. Examples include:

- ✓ People living with a disabled /ill caregiver;
- ✓ LEA/residential placements needing agency funding to continue placements within one year;
- ✓ Medical/behavior needs extensive creating stress on the family or current living situation;
- ✓ An individual who can no longer live with aged caregiver(s);
- ✓ An individual living with a single caregiver who would be unable to work if services are not provided.

Projected Service Need: A projection of needed services other than priority needs which exist currently or are expected to be needed within the next two years. No one below the age of 16 would appear on the projected service needs list. Examples include:

- ✓ Individuals living with aging caregivers who are expected to need services within the next two years;
- ✓ Students graduating next year who will have no continued supports but will need long-term supports to prevent regression.

Long-term Planning: Those individuals who have been found eligible for services but are not in immediate need of those services. Area agencies will maintain a standardized tracking mechanism for long-term planning.

In addition, on June 6, 1997, New Hampshire Governor Shaheen signed into law a bill (HB 571) that requires the state Department of Health and Human Services to determine the costs of fully funding the entire waiting list population for developmental disabilities services and to include this information in an annual report to the Governor and the Legislature. HB 571 states: “The general court [the legislature] is cognizant of and concerned that so many of the state’s developmentally disabled persons are deprived each year of essential services because New Hampshire has failed to adequately fund those services. Therefore, the general court intends that the department of health and

human services fully fund such services in future budget requests.” New Hampshire’s Department of Health and Human Services is required to deliver annually to the Governor a report on the costs of fully funding the state’s developmental disabilities waiting list.

Ohio maintains a long-term service-planning registry for individuals who wish to record their request for services for the future. “The purpose of the registry is to enable the board to document requests and to plan appropriately” (Ohio statute, 1997).

Connecticut established a planning committee in 1994 that acknowledged early in their work that the “waiting list” may be in reality a combination “waiting” and “planning” list. There are many families who have requested residential placements in anticipation of their future needs but who currently prefer to have their family members live with them. For these families, the list is more of a planning tool than a waiting list. Families have fears about how their family member with a disability will be cared for when they are gone. There is a lack of person and family-centered planning and resources to support those plans. Connecticut is surveying families on the waiting list to sort between persons who need to be served immediately and those who need to plan. The Planning Committee’s proposal to determine whether “new” people are served immediately or helped to plan their future includes:

- ✓ Identify person’s needs and supports (avoid the available product trap);
- ✓ Identify what it will take to meet their needs;
- ✓ Identify potential resources to meet needs--not only what exists, but what could be created;
- ✓ Identify the time frame within which supports need to be provided.

[Connecticut Planning Report, 1994]

• **Competing Pressures**

Twenty-nine states indicated that there are several significant factors that account for the continued growth of the waiting list.

Deinstitutionalization: Many states are under court order or legislative mandate to move people who live in state-operated institutions to community settings. “We must provide services for members of a class action suit irregardless [sic] of the budget. We are planning to implement our Home and Community-Based Waiver program. However, these resources will be distributed on a first come, first served basis” (Washington, DC, 1997). “Because our state is responding to two lawsuits regarding its institutions, our priority for community services currently focuses on the persons who are presently living in those centers” (Tennessee, 1997).

Nursing Homes: Early proponents of the deinstitutionalization movement were eager to reduce the number of individuals living in large public institutions. Initial efforts moved a large number of people with mental retardation and other developmental disabilities into nursing homes. Nursing homes were also used to avoid placement in large public institutions. Unfortunately, many of these nursing facilities were not designed to meet the needs of people with developmental disabilities. States are challenged to meet the

Omnibus Budget Reconciliation Act (OBRA-1987) to develop alternative living options for many people with MR/DD who live in these homes. “People who are currently residing in a nursing facility and requesting placement will be among the first priority for Home and Community Waiver funds” (Arkansas, 1997).

People living in the Community: All 29 states acknowledged the most serious obstacles in gaining access to the MR/DD service delivery system appear to be present for the following groups of people: 1) families with young adults who have graduated from special education programs and who are waiting for vocational, habilitation, and community residential services; 2) parents of adult family members with mental retardation and other developmental disabilities who want them to remain at home but are seeking respite and other support services; and 3) elderly parents of adult children who are seeking out-of-home placement for the first time. These groups are in constant competition for limited resources. “Due to the intense competition for resources, the legislature set aside some portion of each allocation for new residential services specifically for individuals living at home” (Connecticut, 1994). “Our system is in gridlock, with new people getting into the system only when someone leaves, and/or when a crisis creates the necessity to band-aid something together” (Kentucky, 1997).

Collectively, state policymakers agree that “moving people from institutional settings to community residences is an important priority” (Kansas, 1995). State planners are also challenged to make necessary adjustments to the system to develop a more inclusive model for service delivery.

- **Financing Strategies**

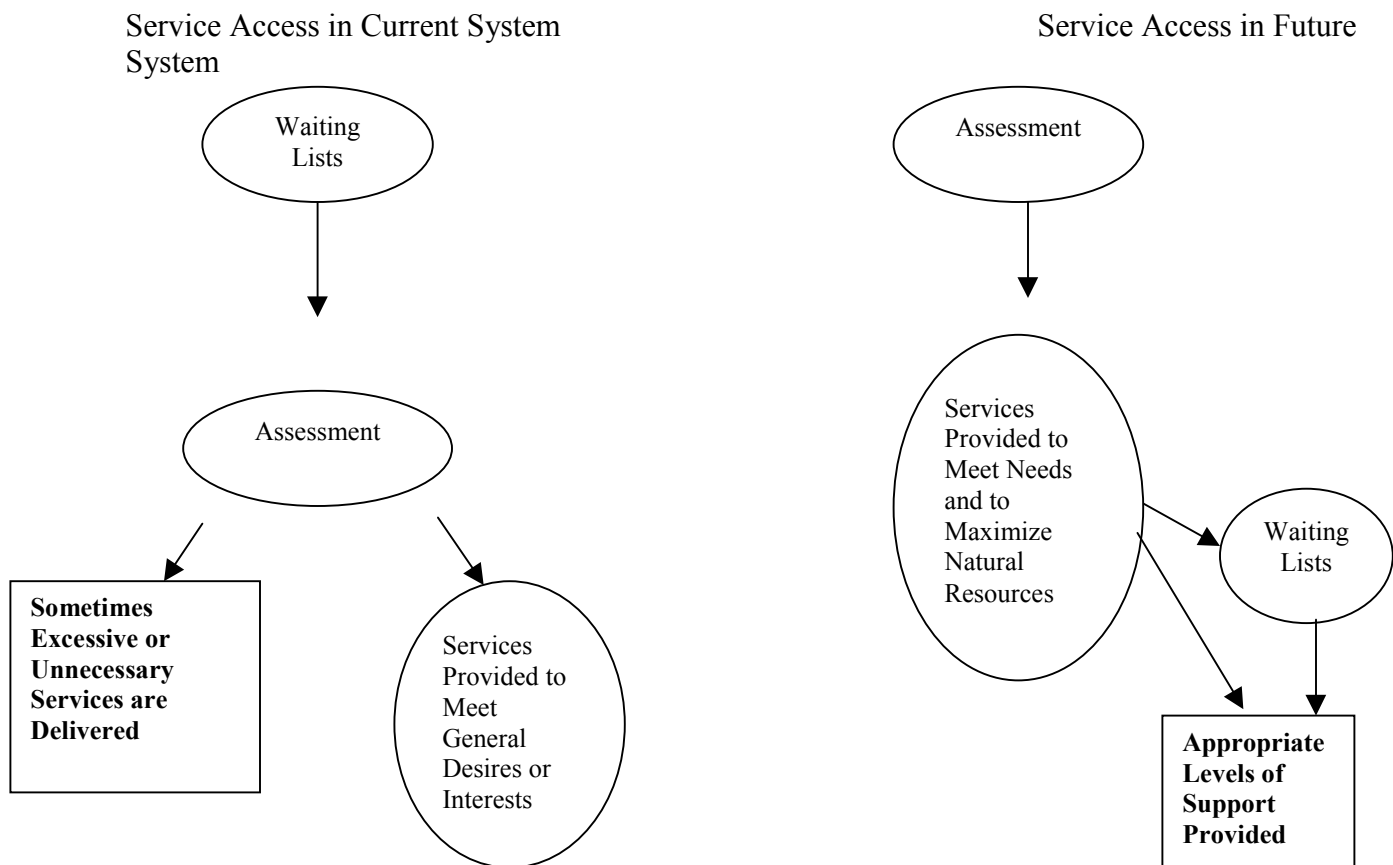
Virtually every state reported that funding was the major obstacle in providing additional supports and services to individuals on the waiting list. Several states, however, have employed creative strategies in addressing ever-expanding waiting lists. The strategies presented include:

- *Target resources to particular age groups.* Nebraska and the state of Washington have earmarked funds within their legislative appropriations to pay for appropriate day supports for every young adult scheduled to age out of special education during the upcoming school year.
- *Restructure funding models to allow individuals and families the ability to make their own choices concerning the services and supports necessary to achieve their personal goals.* Michigan is moving their Medicaid-funded service system into a managed-care model. “We must make significant changes if our system is to become more productive. We know that there must be more flexibility in how dollars are employed to support people in their communities. We must rely less on prescriptive, highly regulated program models, and we must confront the problem of the uneven distribution of resources.” The intended outcome is to utilize any “savings” achieved by employing managed-care strategies to furnish services and supports to other individuals.

Virginia has proposed a revised framework for delivering publicly-funded services and supports. The guiding principles include 1) assuring least intrusive/least restrictive supports, 2) distributing resources responsibly, 3) maximizing personal resources and natural supports, and 4) individualizing supports. Virginia has identified a process that emphasizes “authentic outcomes” such as a job, roommate, and respite care for family preservation, and integration into generic community activities. Virginia has restructured services so that families receive the least intrusive level of support (See Table 5).

Nevada rewrote its Home and Community-Based Waiver to specifically target people who are on the waiting lists. The primary focus for people on the waiting lists is now family support. “We are remaking our service system based upon what people need versus merely what we have to offer” (Nevada, 1997).

Table 5
Virginia System of Supports



- *Restructure the state’s reliance on high cost services and reinvest the savings in supports for unserved and underserved on waiting lists.* According to the Connecticut plan, entitled DMR 2000, “almost half of the present service recipients consume 86% of the resources.” Consequently, Connecticut is redistributing and restructuring resources and working with its legislature to reinvest retained federal revenue funds to free up approximately \$4 million for individuals on the waiting list. A renewed emphasis will be placed on developing services and

supports that are family-driven, consumer friendly, cost effective and available to families who have been without services for many years.

New York has closed ten institutions since 1986 with a renewed focus on developing more individualized supports and services for families. A revised Home and Community-Based Waiver has allowed New York to serve more than 27,000 individuals.

Minnesota has reduced the number of large state-operated facilities and has expanded the capacity of local communities to support persons with disabilities and their families.

Wyoming State Training School, the state's only Intermediate Care Facility for the Mentally Retarded (ICF/MR), was closed in 1997. As individuals were moved to community settings, state dollars were transferred to allow for expansion of the community system.

New Hampshire will divert 300 individuals from nursing home placements to community-based services. A portion of the savings will be used to support people on the waiting list.

- *Establish collaborative strategies with all key stakeholders in the service system.* Many states acknowledged that a crucial step in eliminating waiting lists is to obtain consensus around future policy directions. New York's Housing and Services Policy identified the need to include "stakeholders in developing and implementing policy and process." The Georgia State Commission on Mental Health, Mental Retardation, and Substance Abuse has also moved in this direction, adopting a set of principles emphasizing the need to improve coordination and collaboration with all public/private agencies serving related constituencies.
- *Establish multi-year strategies designed to improve system-wide access.* Connecticut, Georgia, New Hampshire, New York, and New Jersey cited the need to prioritize, analyze and plan innovative strategies targeted to the waiting list population.

New Hampshire "actively reviews and manages their waiting lists" in every area agency. A variety of strategies have been employed to reduce the number of families who are in need of service. These include: 1) renegotiating contracts with vendors; 2) slot sharing; 3) re-examining individual needs for supports, 4) converting residential vacancies to community support, family support or other less costly services; 5) utilizing general fund dollars to provide the 50% match for Medicaid; and 6) providing partial services which temporarily assist the individual.

Connecticut's planning report acknowledged that the current service delivery system must be "reconfigured in order to equitably distribute resources among those currently receiving services and those not receiving services." The long-term strategies cited in the report include: 1) differentiate between a waiting list and a planning list; 2) switch to person-centered funding; 3) establish a dedicated account for individuals on the waiting list -- a portion of federal reimbursements should be earmarked for this account; 4) develop alternate support options; 5) increase flexibility in funding mechanisms.

States indicated that resolution of waiting lists would occur only when stakeholders examine the entire service delivery system. Adjustments made to the system need to be made in the

spirit of equal access to services. States agreed that planning must begin immediately if they are to alter the course of service development in the future.

Recommendations

In order to enhance access to services for adults with MR/DD, states have examined the obstacles to expanding service development and identified strategies to overcome these constraints. Many states have developed financial strategies that include flexible and individualized funding approaches, increased family support services and improved collaboration among state and local governments and community service providers. The following recommendations are strategies for enhancing access to services:

Develop a multi-year strategy designed to enhance system-wide access. States that have been successful in reducing their waiting lists have reconfigured their service delivery systems for persons with mental retardation in order to distribute resources equitably among those currently receiving services and those not receiving services.

Differentiate between a waiting list and a planning list. States need to track who needs services and what types of services are being requested. States need to be able to respond to individuals who are in immediate need of assistance and plan accordingly for those who are seeking information and referral for future development.

Develop a comprehensive data collection system. States need to collect data that can become a meaningful tool for planning and policy development. States need to develop better mechanisms for collecting, analyzing, and disseminating information.

Educate and involve key stakeholders. States need to educate the public, legislators, community leaders, families, and policy makers about issues and recommendations. Building partnerships is essential to developing community connections and support.

Increase flexibility in funding mechanisms. States need to better understand creative finance strategies that will enable government and the private sector to provide needed services and supports. State procurement mechanisms must be restructured to support individual needs and personalized services.

Conclusion

Hayden and Abery remind us that “[w]aiting lists can become permanent indicators of our society’s inability or unwillingness to respond to the needs of individuals. At their worst, waiting lists are indicators of system crisis and failure, but we can use waiting lists for community-based services as meaningful tools for planning and policy development” (1994). This study confirms that growing waiting lists are a nearly universal problem. Yet this survey also shows that many states have developed and begun to implement substantive reform that not only expands the pool of service recipients but promotes models that are cost-effective and person-centered as well.

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